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Title: Current therapy for the upper-limb after stroke: a cross-sectional survey of UK therapists

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Abstract

Objectives: To survey the reported content, frequency and duration of upper-limb treatment provided by occupational and physiotherapists for people after stroke in the UK.

Design: An cross-sectional online survey was used. Description and analysis of the data were based on items from the Template for Intervention Description and Replication (TIDieR) (Who, Where, What and How much).

Setting: The online survey was distributed via professional and social networks to UK-based therapists.

Participants: Respondents were occupational or physiotherapists currently working clinically in the UK with people after stroke. Over the 6-week data collection period, 156 respondents opened the survey, and 154 completed it. Respondents comprised 85 physiotherapists and 69 occupational therapists.

Results: Respondents reported treating the upper-limb a median of three times a week (range: 1-7) for a mean of 28 minutes (SD: 19). Most (n=110) stated this was supplemented by rehabilitation assistants, family and/or carers providing additional therapy a median of 3 times a week (range 1-7). Functional training was the most commonly reported treatment for people with mild and moderate upper-limb deficits (>40%). There was much less consistency in treatments reported for people with severe upper-limb deficits with less than 20% (n=28) reporting the same treatments.

Conclusions: This study provides a contemporaneous description of reported therapy in the UK for people with upper-limb deficits after stroke and a detailed template to inform standard therapy interventions in future research. Several evidence-based therapies were reported to be used by respondents (e.g. constraint induced movement therapy), but others were not (e.g. mental imagery). The findings highlight that the current reported provision of upper-limb therapy is markedly less than what is likely to be effective. This underlines an urgent need to configure and fund services to empower therapists to deliver greater amounts of treatment for people with upper-limb deficits after stroke.

Keywords: Upper limb; rehabilitation, stroke, therapy, survey

Strengths and limitations:

- The survey findings provide key detail about the frequency, intensity and content of therapy for differing severities of arm deficits after stroke
- Unlike other surveys of therapy, the results also describe supplemental activities delivered by rehabilitation assistants and family/carers
- Its findings can be used to design a standard therapy control intervention for future trials of upper-limb interventions
- The findings of the survey are limited by its reliance upon self-report and an unknown response rate

Background

Over 100,000 people have a stroke each year in the UK[1]. Improvements in acute medical care mean that more people survive than ever before, but many need significant rehabilitation to restore function. Whilst two-thirds of people go on to walk independently after stroke, less than half have regained basic functions of the upper-limb by 12 months, which markedly restricts their independence in activities of daily living and reduces their quality of life[2,3]. This makes upper-limb rehabilitation a significant and ongoing priority for people after stroke, clinicians and researchers.

An understanding of what current clinical therapy comprises is vital to allow comparisons to guidelines and the research evidence-base to determine how well research evidence is being translated into routine practice and to inform therapy provision. Furthermore, many trials in stroke rehabilitation compare experimental treatments to a standard or usual therapy, in order to evaluate the potential equivalence or superiority of new interventions. The increasing use of reporting guidelines to describe trials and interventions, such as the TIDieR checklist (Template for Intervention Description and Replication)[4] has encouraged more detailed description of many experimental treatments in research trials. However, the same rigour in reporting is often not applied when describing standard therapy in studies evaluating rehabilitative interventions in stroke[5]. In stroke rehabilitation trials almost half the number of words and references are used to describe and support control treatments compared to the experimental intervention[5]. Underreporting of the components of standard treatment presents problems in the design, interpretation and implementation of stroke rehabilitation trials. Firstly, it reduces confidence that participants in a standard therapy control arm received a clinically representative intervention, and so negatively impacts upon the veracity of the trial's results. Secondly, readers of published trials may struggle to interpret differences between groups where one treatment (the standard therapy group) is ill-defined and/or unrealistic and make erroneous conclusions about the superiority of one treatment over another. Thirdly inadequate description means as it cannot be determined if standard therapies delivered across trials are similar, results from multiple studies cannot be compared and the opportunities for synthesis and meta-analysis are reduced.

In the last 10 years, the number of studies of interventions focussed on rehabilitation of the upper-limb after stroke has grown rapidly (354 studies published in 2006-2007 to 943 studies published in 2016-17; Pubmed search using stroke AND upper-limb). Despite this increase in research activity, recovery and rehabilitation of the upper-limb after stroke remains a significant challenge, and so it is likely to continue to be a focus of research endeavour for many years to come. Consequently, accurate reporting of standard therapy/treatments is vital to inform future trial design and to ensure that their results are easily interpretable and reproducible.

In the UK, audits such as the Sentinel Stroke National Audit Programme (SSNAP) provide an indication of temporal elements of therapy (e.g. average treatment time) but not provide any indication of what treatment comprises[6]. Several studies have sought to describe aspects of therapy provided in rehabilitation of the upper-limb after stroke. Some have reported the content of therapy for the upper-limb used in clinical trials[7,8] but treatments delivered as part of a clinical trial may not necessarily reflect therapy routinely delivered in clinical practice . Similarly, others have developed upper-limb treatment templates to standardise therapy in research trials[9–11] however these templates seek to guide therapy or record current treatment, and so do not describe routine clinical practice. Several researchers have observed the number of repetitions, time given to, and overall dose of therapy occurring during clinical therapy sessions for the upper-limb [8,12–14] and others have observed and recorded the time spent on activities whilst staying in rehabilitation facilities [15–19]. Whilst these observational studies yield perhaps the most objective information

about the intensity and provision of therapy, they are based on reports from a small number of international sites which limits their applicability to wider practice in the UK. Crucially, they do not typically provide details of the specific content of therapy.

In the UK, two studies have used surveys to gather information about therapy for the upper-limb after stroke. One national survey in the UK found that exercises are prescribed by nearly all therapists for the upper-limb of people after stroke, but did not investigate the content or duration of treatment undertaken with therapists[20]. Others have surveyed UK stroke teams and used the opinions of expert panels to describe the duration, frequency and content of upper-limb rehabilitation provided by UK stroke teams [21] but did not consider the detailed content of activities nor those performed outside therapy sessions. It is also worth note that both these studies were conducted several years ago, prior to publication of the latest Stroke Guidelines in 2016[22] which may have altered practice.

Without a contemporaneous and detailed definition, standard therapy in rehabilitation trials for the upper-limb after stroke risk being biased, unrealistic and unreflective of current clinical therapy, affecting the validity and usefulness of the trial results. Furthermore, a description of current clinical practice is needed to evaluate the implementation of research findings into therapeutic practice and to understand 'the state of the art' in upper-limb stroke rehabilitation in the UK. Therefore, this study aims to describe the reported content, frequency and duration of upper-limb therapy for people after stroke in the UK.

Methods

A cross-sectional online survey – the Survey of Upper-limb Therapy after Stroke (SUPPLES UK) was developed by 2 occupational and 2 physiotherapists and comprised 44 closed, Likert and free text items, was developed using the Online Surveys tool (www.onlinesurveys.ac.uk; formerly known as Bristol Online Surveys). Questions were developed using the current UK stroke guidelines and previous investigations of the provision of upper-limb therapy after stroke [20–22]. The survey and item structure were guided by identified good practice in survey construction and the Template for Intervention Description and Replication (TIDieR) to facilitate replicable reporting of the content, frequency and duration of the reported therapy [4,23]. Sections included:

- Respondent demographics,
- Staff involved in delivery of therapy
- Content, frequency and dose of therapy
- Other activities/therapy provided outside of therapist-led treatments

Respondents were asked to indicate treatments that they typically used for different severities of upper-limb impairments after stroke, defined from the NIH Stroke Scale upper-limb item (0,1=mild- able to lift and hold arm up against gravity for 10 seconds, 2=moderate - some effort against gravity, but the arm cannot get to or maintain the proper position and drifts down to the bed before 10 seconds, 3 and 4= severe – unable to move against gravity or no voluntary movement)[24].

The survey was piloted by three therapists, peer-reviewed and refined according to feedback. The final survey was distributed via professional channels, (Association of Chartered Physiotherapists Interested in Neurology, ACPIN, Royal College of Occupational Therapists- neurological section, RCOT-NS, Physiotherapy Frontline) and social networks (Twitter). It remained open for six weeks (1st July to 13th August 2018). No patient or public involvement was included in this work.

Respondents were provided with an information sheet (online) and consent was implied by completing the survey. They completed the survey anonymously, having first confirmed they were occupational or physiotherapists and that they were currently clinically working with stroke survivors.

The survey gained ethical approval from the Science Technology, Medicine and Health Ethics panel at the University of Central Lancashire (reference number: 869).

Analysis

Demographic details, treatment frequencies and durations were summarised using descriptive statistics. Interval level data were reported using means and standard deviations, whilst ordinal and nominal data used median and ranges. As some respondents worked across settings, their primary location of work was assumed to be where they spent at least 75% of their time. Where a range was provided by respondents in free-text answers (e.g. 20-30 minutes), the mean average was used and weekly frequencies were expressed as a fraction of 7 days a week (e.g. every day= 7). If respondents reported providing treatments more than once a day, this was expressed as a multiple (e.g. twice daily treatment every day=14). Free text answers were initially listed and then coded into themes by one person (RP), and independently verified by another (RS). Any disagreements in coding were resolved by a third person (LC or KJ). The TIDieR framework was used to structure the analysis and presentation of results. This paper reports who provided treatments (Who), where respondents were based (Where), treatment content (What) and frequency and duration (When and How much). Analyses were undertaken using MS Excel and SPSS version 23.

Results

Respondent demographics

One hundred and fifty-six people completed the two mandatory questions (confirming that they were an occupational or physio therapist and that they were currently clinically working with stroke survivors at any stage of their recovery in the UK). Two respondents' data were excluded from further analysis as they had more than 50% of data missing. Respondents came from all over the UK and Northern Ireland (see Figure 1). A TIDieR checklist was completed using the results and is presented in the Appendix.

Figure 1 – Geographical location of survey respondents (n=154) (©Google Earth)

Who?

Respondents comprised slightly more physiotherapists (PT) than occupational therapists (OT; 85 physiotherapists; 69 occupational therapists). The majority of respondents reported an undergraduate degree as their highest qualification (n=79), 40 had a master's degree and 9 had a PhD. Nine had completed some master's modules and/or had some postgraduate qualifications (PG cert or similar) whilst others stated that a diploma was their highest academic qualification (n=15).

Respondents were a mean average of 16.9 years since qualification (SD 8.8; range 1-36; n=155). On average, respondents had worked with people after stroke for a mean of 12.4 years (SD 9; 1-27; n=154). They reported spending 70% of their clinical time working with people after stroke (SD:30; 8-100; n=153) and of their clinical caseload, they estimated that 38% (SD18, range:2-80) had severe 34% (10, 18-60) had moderate and 28% (16, 10-80) had mild arm deficits.

Respondents identified other providers of treatment in addition to therapists included rehabilitation assistants (n=44), family/carer/friend (n=47) nursing staff (n=5), volunteers (n=3).

Where?

The majority of respondents were employed in the NHS (80%; n=132) with less than 15% (n=25) working the private sector and 2% working in a voluntary/third sector (n=4) or high education setting (n=3).

Therapists (n=154) worked in a variety of settings. From those that reported spending over 75% of their time in a single setting (n=76) 30 worked in Hyperacute/acute settings (39%), 10 in general inpatient rehabilitation (13%), 2 in intermediate care (3%), 18 in early-supported discharge (24%), 11 in general community (15%) and 5 (7%) in outpatients. The remainder (n=78) did not spend more than 75% of their time in a single setting.

What?

Participants were asked to list treatments that they typically used for people with mild, moderate and severe deficits [24] (defined using the NIH Stroke Scale) of the upper-limb after stroke.

Mild deficits

Respondents reported spending 41% (SD 26, 7-100) of a typical therapy session on treatments for the upper-limb for people with mild deficits. In free text answers, respondents (n=151) listed 30 treatments/interventions that they would typically use as part of treatment. Those used by more than 10% of respondents are shown in Table 1

Table 1 Treatments used for people with mild upper-limb deficits listed by over 10% of respondents

Treatments	N	%
Functional training	101	67
GRASP	53	35
Active and weighted exercise	29	19
CIMT	25	17
Task repetitive strength training	21	14

GRASP – Graded Repetitive Arm Supplementary Programme, CIMT – Constraint Induced Movement Therapy

Seventy-one percent (n=110) of respondents reported that people with mild deficits of the upper-limb were also given unsupervised activities in addition to that provided during sessions with occupational or physiotherapists. This comprised functional training/practice (n=90), exercise programmes (n=58), GRASP and PRACTISE (Promoting Recovery of the Arm: Clinical Tools for Intensive Stroke Exercise) structured upper-limb exercise programmes (n=49), Remedial/table top activities (e.g. theraputty; n=30) and sensory re-education (n=17).

Moderate deficits

In a typical treatment session, respondents reported spending approximately 45% (SD17; 20-90) of the entire session on upper-limb activities for people with moderate deficits. Respondents (n=150) listed 25 different treatments for people with moderate arm deficits after stroke, those used by more than 10% of respondents are shown in Table 2.

Table 2 Treatments used for people with moderate upper-limb deficits listed by over 10% of respondents

Treatments	n	%
Functional Training	63	42
Active and weighted exercise	58	38
GRASP	52	35
Mirror box treatment	29	19
CIMT	23	15

GRASP – Graded Repetitive Arm Supplementary Programme, CIMT – Constraint Induced Movement Therapy

Ninety-five percent of respondents (n=143) reported that people with moderate arm deficits were given additional unsupervised activities. These comprised exercise programmes (n=70), practice of functional/everyday tasks (n=50), Sensory re-education (n=36), GRASP and PRACTISE structured upper-limb exercise programmes (n=34), mirror therapy (n=14) and positioning (n=14).

Severe deficits

Respondents estimated that they spent 35% (SD19, 10-90) of a typical treatment session on upper-limb treatments for people with severe deficits. From free text answers, respondents (n=147) listed 16 different treatments for the upper-limb in this group. The treatments reported to be used by over 10% of respondents for this group are displayed in Table 3.

Table 3 Treatments used for people with severe upper-limb deficits listed by over 10% of respondents

Treatments	n	%
Range of Movement exercises	28	19
Mirror Box treatment	20	14
Functional Electrical Stimulation	20	14

Seventy-nine percent of respondents (n=119) reported that people with severe arm deficits typically received additional unsupervised therapy to that provided by physio and occupational therapists. This included exercise programmes (n=66), Sensory re-education/massage (n=42), positioning (n=39), advice and education (n=33), mirror therapy (n=12) and splinting (n=12).

When and how much?

Frequency

Respondents reported that occupational and physiotherapists provided treatment for the upper-limb a median average of three times a week (range PT: 1-7 days; OT: 1-6 days). The frequency varied depending upon setting (Figure 2) with patients in inpatient settings receiving somewhat more frequent treatment than those in general community and outpatient settings.

Figure 2 Reported median frequency of therapy provided each week according to location

Error bars denote interquartile range.

One hundred and ten respondents stated that treatment by others was provided in addition to occupational and physio therapy, whilst 44 reported that no additional therapy was provided. For those indicating that additional therapy was provided it was given a median of 3 times a week by rehabilitation assistants (n=47; range 1-7) and on a daily basis by family/carer/friends (range:3-7; n=44).

Duration

Within each therapy session, respondents estimated typically spending a mean average of 28.4 minutes (SD19, range:7.5-80) directly engaged in upper-limb treatments ("time on task"). This varied depending upon where the patient was based (Table 4).

Table 4 Mean reported time spent on upper-limb in treatment session

Location	N	Mean time (minutes, SD)
Hyperacute/ acute care	29	21.4 (14.2)
Early supported discharge	18	23.8 (12)
General rehabilitation	10	25.5 (14.4)
Intermediate care	2	25 (7)
General community	10	20.5 (15.2)
Outpatients	5	32 (15.2)

A completed TIDieR checklist and collated data is presented in supplementary tables I and II in the appendix.

Discussion

This study utilised elements of a recognised reporting tool, the TIDieR checklist (presented in Appendix I)[4], to develop a survey to describe the content of usual therapy reported by occupational and physiotherapists for the upper-limb after stroke. Respondents appeared largely representative of the wider UK therapist population, demonstrating a range of academic qualifications, experience and geographical location. By aligning reported therapy practice across the UK to items of the TIDieR checklist, the survey findings can be used to design clear and replicable standard therapy control interventions to inform future research trials. Furthermore, by providing a detailed description of reported current practice this study highlights gaps between recommended treatments from guidelines and their implementation in clinical settings, guiding future research and rehabilitation service configurations. However, the survey findings have several limitations. The response rate of the survey is not known because it was distributed electronically via multiple channels. The ACPIN database, which was one channel through which it was circulated, contains over 1000 members, suggesting that the survey's response rate was relatively low but not unexpected for this type of survey[25]. Efforts were made to increase responses through reminder emails and the use of the professional organisations for distribution provided credibility and anonymity. As the sample size was over 150 the sampling error was reduced[25] but should still be acknowledged. It is also worth of note that there were very little missing data, with only two (subsequently excluded) respondents omitting more than 50% of items. This suggests that although some people chose not to open the survey, those that did completed it diligently. It is also likely that respondents were motivated and interested in upper-limb rehabilitation, indicating some unavoidable bias in their responses.

The survey found that, on average, respondents reported providing upper-limb therapy for 28 minutes three times a week, although both these parameters varied depending on the setting. An

interesting finding was that the reported average time of upper-limb treatment per session was considerably more than that reported in observational studies. In a systematic reviews, between four to 17 minutes of therapy was spent on upper-limb treatments in a treatment session[26][8]. The greater intensity of therapy reported in this survey could indicate a selection bias as those therapists who were motivated and able to provide more upper-limb therapy might have been more likely to complete the survey. It could also suggest, as observed by others, that therapists may have over reported the actual time spent on treatment [27]. However, the differences in findings between studies might reflect different interpretations as to what upper-limb therapy actually comprises[28]. This ambiguity might be an inevitable limitation of the current study's findings, but focus on content of therapy and who delivered it attempted to minimise this effect by providing some guidance to therapists on what did, and what did not, constitute therapy.

An unanticipated and novel finding is the majority of respondents noted that they provided additional activities and that others supplemented therapy for people after stroke. On average this was provided on a daily basis by family/carers (n=44) and three times a week by rehabilitation assistants (n=47). This is the first study to highlight the provision of additional therapy as a component of standard therapy and indicates that this extra input should be recognised when considering replicating standard treatment in trials. Despite this, the findings of this survey indicate that the reported overall dose of therapy is relatively small when compared to what is known to be effective from animal models of stroke rehabilitation[29] and so may not realise the potential for recovery. This argument is supported by findings from other studies; several large, well-conducted trials offering similar amounts of upper-limb therapy to those reported in the current study found minimal benefit[30,31] whilst trials that used higher doses reported meaningful and significant changes[32]. In addition to research trials, large improvements in upper-limb functioning have been reported in an NHS-funded clinical service (the Queen's Square Upper-limb Programme) that delivers 90 hours of multidisciplinary upper-limb rehabilitation over three weeks[33]. When the intensities of therapy in these studies are compared to those measured in observational studies[28,34], SSNAP data[6] and the current study, they emphasise that service provision for rehabilitation of the upper-limb after stroke needs radical alteration if it is to empower therapists to provide effective therapy and maximise recovery for people after stroke. Further research is therefore urgently needed to find ways to upscale services so that they can deliver greater intensities of high-quality, evidence-based therapy for the upper-limb that can be provided in clinical practice.

The findings indicate that several well-evidenced and recommended clinical treatments (e.g. the Constraint Induced Movement Therapy and the Graded Repetitive Arm Supplementary Programme) were reported to be used by many respondents. Interestingly, repetitive task training, a treatment in which participants repeatedly practice a task or goal oriented movement, was not explicitly listed by any participant, despite being recommended in guidelines and supported by a relatively robust evidence base [22,35]. However, it is possible that respondents' use of 'functional training' to describe their treatments could have been analogous to repetitive task training, but this cannot be verified. Some respondents did report using 'task specific strength training' (mild: n=21; moderate: n=11) but, as this terminology is not widely utilised in rehabilitation literature it is unclear what it comprises. The focus of therapy towards functional activities found in this study supports other reports of practice in the UK[21] and treatments those for mild and moderate upper-limb deficits showed considerable similarities between respondents. Whilst others have reported somewhat greater consensus for the use of functional activities in therapy (over 88% for mild and moderate deficits), this may be due to different survey approaches and the use of an expert panel to assimilate data[21]. In contrast, there was a notable lack of consistency in the treatment choices reported for

people with severe deficits of the upper-limb; the most commonly given treatment (range of motion) was only listed by 19% of 107 respondents. This may reflect therapists' uncertainty about the recovery of the severely impaired upper-limb and the current absence of specific guidance and established effective therapies for rehabilitation after severe stroke[36]. It is also possible that the variability in treatments for those with severe deficits is because of the influence of other factors which tend to accompany more severe deficits after stroke (for example worse pre-stroke status, older age and medical complications). Indeed, it has been found that patients who had a milder stroke, were younger, male, had fewer medical complications and had received thrombolysis tended to receive more intensive therapy after stroke[37]. These findings highlight that better understanding of the factors that influence clinicians' professional decision making about treatment content and intensity is worthy of further investigation to guide clinical care. The findings also showed that other evidence-based and recommended treatments (such as mental imagery and mirror therapy) are not widely implemented in clinical practice[22]. This is perhaps not surprising as only a small fraction (2.5%) of published stroke rehabilitation research in journals evaluate the implementation of evidence-based interventions into health care practice[38] and further investigation is warranted to determine why some treatments were implemented and others were not. This suggests that a greater focus on how established effective treatments can become part of routine clinical care is needed.

Conclusions

This survey has identified the commonly reported upper-limb treatments that are provided for people after stroke by occupational and physiotherapists. These results are not intended to provide an exemplar or template for clinical practice or represent best practice and are limited by an unknown response rate and the self-reported nature of the data. However, they can be used to reflect current practice in the UK and provide a detailed point of reference to aid the development of standard therapy interventions in research trials and a contemporaneous picture of current therapy in the UK.

The findings indicate that some evidence-based treatments appear to be more widely implemented in routine clinical practice (e.g. CIMT) than others (e.g. mental imagery) and that whilst there is considerable consensus in the treatments used for mild and moderate upper-limb deficits, there was much less consistency in the treatments used with people with severe deficits. The results also indicate that the intensity of therapy is less than that shown to be effective in rehabilitation studies.

Future work could seek to needed to identify the optimally effective treatments for different severities of upper-limb involvement after stroke and qualitatively explore the rationale for treatment selection. Finding ways to deliver more intensive therapy in practice is also urgently required and the development of new treatments should explicitly consider how they can be adopted into clinical practice. The findings of the current study contribute to these endeavours by providing a detailed description of currently reported, clinically realistic upper-limb therapy which informs the design, interpretation and implementation of future stroke rehabilitation research.

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Author Contributions

RS developed the idea and undertook analysis of the results and drafted the paper

RP conducted analysis of the data and drafted the paper

LC developed the idea, oversaw analysis and drafted the paper

KJ developed the idea, oversaw analysis and drafted the paper

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Competing interests

The authors have no competing interests.

Data sharing

At this current time, we do not have facilities to make raw data available to readers. However, we are looking to resolve this and by the time the paper would be published we hope to be able to provide online access to the raw data.

Appendices

The SUPPLES-UK questionnaire

Protocol for the study

Complete TIDieR checklist

Supplementary Tables I and II

Figures 1 and 2

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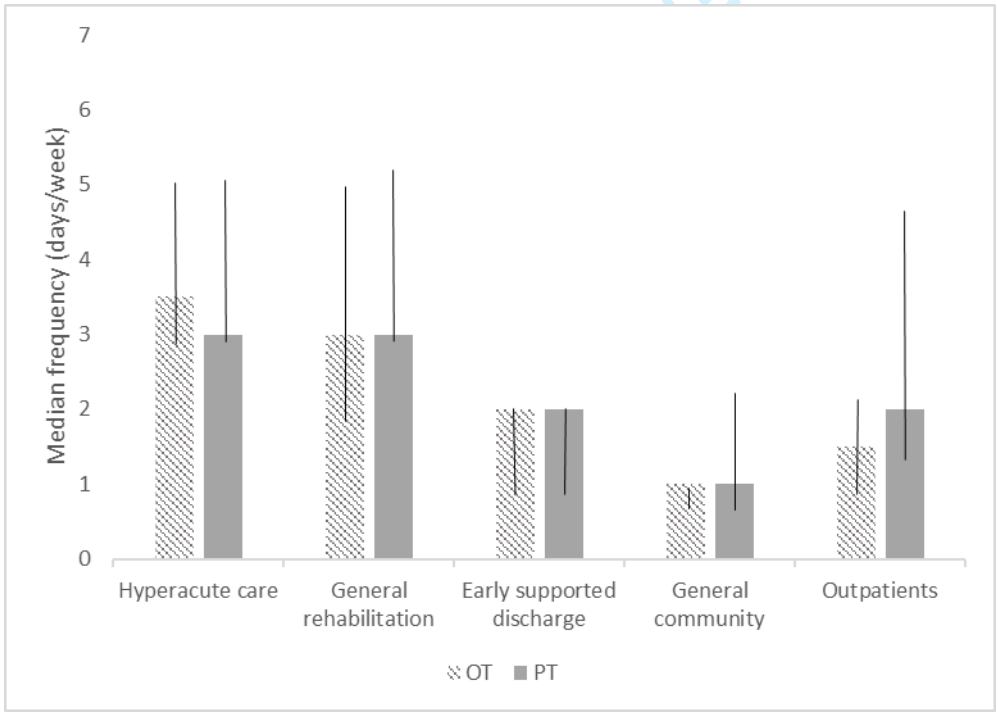
Figures

Figure 1 – Geographical location of survey respondents (n=154) (©Google Earth)

Figure 2 Reported median frequency of therapy provided each week according to location



Error bars denote interquartile range.

Appendix I

Table to show TIDieR checklist items Who, Where and How much for upper limb treatments

Who delivered therapy?	Where?	How much – Frequency(sessions/week, median, range)	How much – Duration(minutes/session, mean, SD)
Occupational Therapists	Hyperacute/Acute Stroke Unit	3.5 (4)	27 (17)
	General Rehabilitation	3 (3)	29 (15)
	Early supported discharge	2 (2)	28 (13)
	General Community	1 (1)	25 (13)
	Outpatients	1.5 (1)	48 (4)
Physiotherapists	Hyperacute/Acute Stroke Unit	3 (4)	16.8 (10)
	General Rehabilitation	3 (3)	16 (12)
	Early supported discharge	2 (3)	23 (12)
	General Community	1 (3)	19 (17)
	Outpatients	2 (1)	22 (8)
Additional therapy			
Rehabilitation assistants	-	3 (6)	-
Family/Carer/Friend	-	7 (4)	-

Appendix II

Table to show 'What?' TIDieR item: Treatments reported by over 10% of respondents for different severities of upper limb deficits

Severity	Mild (UL NIHSS score of 0 or 1)	Moderate (UL NIHSS score =2)	Severe (UL NIHSS: 3 and 4)
Treatments	Functional training	Functional Training	Range of Movement exercises
	GRASP	Active and weighted exercise	Mirror Box treatment
	Active and weighted exercise	GRASP	Functional Electrical Stimulation
	CIMT	Mirror box treatment	
	Task repetitive strength training	CIMT	

UL NIHSS – Upper limb National Institute of Health Stroke Scale upper limb item: 0,1= able to lift and hold arm up against gravity for 10 seconds, 2= some effort against gravity, but the arm cannot get to or maintain the proper position and drifts down to the bed before 10 seconds, 3 and 4= unable to move against gravity or no voluntary movement. GRASP – Graded Repetitive Arm Supplementary Programme CIMT – Constraint Induced Movement Therapy

TiDieR

Describing current therapy in the UK for the upper limb after stroke

Details:	Current Upper Limb therapy
Why:	NA
What (material):	NA
What (procedures):	**Mild (UL NIHSS =0 or 1)** Functional training GRASP Active and weighted exercise CIMT Task repetitive strength training **Moderate (UL NIHSS =2)** Functional Training Active and weighted exercise GRASP Mirror box treatment CIMT **Severe (UL NIHSS = 3 and 4)** Range of Movement exercises Mirror Box treatment Functional Electrical Stimulation
Who provided:	**Occupational Therapists** **Physiotherapists** **Additional therapy** Rehabilitation assistants Family/Carer/Friend
How (mode of delivery; individual or group):	Face to face.
Where:	In the UK. Hospital based: Hyperacute/Acute Stroke Unit, General Rehabilitation, Community based: Early supported discharge, General Community, Outpatients
When and how much:	

Form saved

Who delivered therapy?	Where?	How much – Frequency (sessions/week, median, range)	Duration (minutes/session, mean, SD)
Occupational Therapists			
	Hyperacute/Acute Stroke Unit	3.5 (4)	27 (17)
	General Rehabilitation	3 (3)	29 (15)
	Early supported discharge	2 (2)	28 (13)
	General Community	1 (1)	25 (13)
	Outpatients	1.5 (1)	48 (4)
Physiotherapists			
	Hyperacute/Acute Stroke Unit	3 (4)	17 (10)
	General Rehabilitation	3 (3)	16 (12)
	Early supported discharge	2 (3)	23 (12)
	General Community	1 (3)	19 (17)
	Outpatients	2 (1)	22 (8)
Additional therapy			
	Rehabilitation assistants	3 (6)	
	Family/Carer/Friend	7 (4)	

Tailoring: NA

How well (planned): NA

Form saved

SUPPLES-UK

Page 1

Thank you for considering completing this survey.

We are a team of occupational and physiotherapy researchers, based at the University of Central Lancashire (UCLan) and we want to describe current UK physio and occupational therapy practice in stroke rehabilitation. By completing this survey, your answers will provide vital information so that we can understand which treatments are being used, how treatments are used and identify factors that influence therapy practice in 2018. This information sheet will tell you more (click here: information sheet)

Before you start: The survey may take around **15** minutes. Although some questions may seem long, please provide as much detail as you can so we can produce a really accurate picture of UK therapy practice.

Completing the survey: Please answer as many questions as you can. You must complete the survey in one sitting as it will not save partly completed questions.

Unsure of how to answer? We know that treatments are personalised to each patient but please answer questions based on your **'average'** practice. Some questions are also more complicated than others. Those that are have guidance to help you answer. To see this please click the 'more info' button beneath the question.

Your privacy: None of your personal details are known to the research team. This survey

will not ask you to share any information that could be used to identify you and all your answers are completely anonymous. All data from this study will be stored securely on password protected PCs/networks. This study has been approved by UCLan's Science Technology Health and Medicine Ethics Committee. You do not need to complete a consent form to participate. By completing and submitting the survey, you are giving consent for us to use your answers for this study.

Want to know more? Please read this information sheet. If you still have any queries, please contact the team (supplesuk@uclan.ac.uk).

Please share! We want as many physio and occupational therapists who work with people after stroke in the UK to complete the survey - please feel free to share the survey link with them.

Section 1 - About you

Are you a Physio or Occupational Therapist working in the UK? ✱ *Required*

- ○ Physiotherapist
- ○ Occupational Therapist
- ○ Not a physio or occupational therapist OR not working in the UK

How many years have you been qualified?

What is your highest academic qualification?

- ○ PhD
- ○ MSc, MA or MEd

- BSc
- Diploma
- Other

If you selected Other, please specify:

How many years have you worked with people who have had a stroke?

Do you currently work clinically with stroke survivors with upper limb deficits at any stage of their rehabilitation? ✱ *Required*

- Yes
- No

Where are you currently employed? *Optional*

More info

- [ ] NHS
- [ ] Private sector
- [ ] Voluntary/Third sector
- [ ] Higher Education
- [ ] Other

If you selected Other, please specify:

Please tell us the first part of the postcode for your primary place of work in the UK (e.g. PR1)

In which setting/s do you usually work? Please provide an approximate percentage of the time you spend in each setting (e.g. 40% Acute Stroke Unit, 60% Neuro-outpatients).

More info

	Percentage of time spent in this area
Hyperacute/Acute Stroke Unit	
General rehabilitation Ward	
Intermediate Care	
Early supported discharge	

General Community	
Neuro-outpatients	
Other	

On average, what percentage of your **clinical** time is spent working with people who have had a stroke?

We are interested in the time you estimate you spend directly engaged in treating people who have had a stroke. Please try to give an accurate and honest approximation.

Within a single treatment session **on average** how many ***minutes*** would you typically spend **directly undertaking *upper limb* treatment** with a person who has **any severity** of upper limb deficits after stroke that is linked to agreed goals (i.e. “time on task” so not including paperwork, MDT meetings, transporting patient to gym etc.)?

More info

Please use this space to tell us anything you feel is relevant to this question.

Section 2 - Delivery of rehabilitation for the upper limb after stroke

We appreciate that the treatment approach used with every patient will differ according to his or her needs and goals after a stroke. However, in this section we are interested in your "***broad approach***" to treatment. Therefore, we would like you to tell us about your **usual practice** when working with a person with upper limb deficits after stroke.

On average, how many days a week does a **typical** person who has had a stroke receive **therapy for their upper limb** delivered by an **occupational therapist**?

If you selected Other, please specify:

On average, how many days a week does a **typical** person who has had a stroke receive **therapy for their upper limb** delivered by a **physiotherapist**?

If you selected Other, please specify:

Section 2 - Delivery of rehabilitation for the upper limb after stroke

After stroke, people will have very varied abilities with their upper limb. For the purposes of this survey, we have divided people into three groups based upon their motor arm function. These are **MILD, MODERATE AND SEVERE** (based upon the NIHSS categories - motor arm).

Please estimate what **percentage** of the people that you see after stroke have arm deficits that would be considered to be:

	%
MILD: someone who is able to move the arm and maintain an arm position against gravity for 10 seconds without physical support	
MODERATE: someone who has some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support	
SEVERE: someone who has no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders)	

Within a **typical** treatment session, what **percentage of the entire treatment session** would you spend on treatments for the upper limb for each of these presentations?

More info

	%
MILD: someone who is able to move the arm and maintain an arm position against gravity for 10 seconds without physical support	
MODERATE: someone who has some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support	
SEVERE: someone who has no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders)	

Outcome Tools

Please list any of the outcome tools or measurements you would commonly use to indicate upper limb ability after stroke.

Key factors affecting upper limb treatment time

We are interested in the factors that **you think typically affect** the direct treatment time of the upper limb. Please tell us how much the following factors influence the time **you spend** undertaking **direct** treatment of the upper limb of a person with arm deficits after stroke.

Please don't select more than 1 answer(s) per row.

	A lot	A little	Not at all
Requirements of external audit (e.g. SSNAP)	☐	☐	☐
Evidence informing treatment dose	☐	☐	☐
Patient factors (e.g. availability and condition)	☐	☐	☐
Staffing levels	☐	☐	☐
Designated time for therapy (e.g. using timetabling)	☐	☐	☐
Time spent in information exchange (handovers, ward round)	☐	☐	☐
Competing priorities (e.g. walking/mobility practice)	☐	☐	☐
Other non-patient contact activities (e.g. organising /ordering equipment)	☐	☐	☐

Please use this space to tell us anything else you feel is relevant to this question. For instance, please tell us if some of these factors have a negative effect (e.g. meaning you spend less time than you would like on upper limb rehabilitation) and/or if other factors that influence the time you spend on upper limb treatments for people after stroke.

Does a person who has upper limb deficits after having a stroke receive any other treatment for their upper limb **in addition** to that received during physiotherapy or occupational therapy?

- Yes
- No

If yes, please tell us who provides this and how often it occurs (e.g. once a week, everyday, three times a day everyday). If you do not know how often it occurs please still tell us about who is involved.

More info

Section 3 - Treatments for the upper limb

In this section, we are interested in the interventions you would use for people who have had a stroke who have mild, moderate and severe arm deficits.

MILD DEFICITS: Please list the treatment interventions you use most often for a person who has had a stroke and is **able to move their arm and maintain an arm position against gravity for 10 seconds without physical support.**

Do you routinely ask a people who have MILD arm deficits to undertake activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

MODERATE DEFICITS: Please list the treatment interventions you use most often for a person who has had a stroke and who has **some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support.**

Do you routinely ask a people who have MODERATE arm deficits to undertake activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

SEVERE DEFICITS: Please list the treatment interventions that you use most often for someone after a stroke who has **no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders**)

Do you routinely ask people with **SEVERE** arm deficits to undertake unsupervised activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

Please use this space below to provide us with any extra information that you think we may find useful. For instance, you may want to tell us about why you use the treatments you use, or why you have chosen not to use some treatments.

Section 4 - Specific Treatments

We are interested in if and how you use **ten** specific treatments. Please indicate how frequently you utilise the following interventions when working with people after stroke with **any severity** of upper limb deficits. If you answer **'never'** to indicate you don't use a treatment you will be re-directed to a question to tell us why.

Section 4 - Specific Treatments

1. How often do you use constraint induced movement therapy (CIMT) of the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

2. How often do you use electrical stimulation for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

3. How often do you use facilitation/handling (e.g. based on the Bobath concept) of the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

4. How often do you use functional activity practice for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

5. How often do you use the Graded Repetitive Arm Supplementary Programme (GRASP) for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

6. How often do you use mental practice/mental imagery for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

7. How often do you use mirror therapy for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

8. How often do you use robot assisted therapy/robotics for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

9. How often do you use strength training for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

10. How often do you use video gaming or virtual reality training for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

Please use this space to tell us about any other treatments that you use and how often you use them.

Additional information about your practice

Please use this space to tell anything else you think is relevant.

Thank you for completing this survey!

We really appreciate the time you have taken to help us understand current therapy practice for the upper limb in the UK.

We are interested in undertaking further research into rehabilitation for the upper limb after stroke and current therapy practice.

If you would like to be kept informed and potentially participate in this work, please email us at supplesuk@uclan.ac.uk.

By emailing us you are consenting to be contacted about future work but are not obliged to take part in any other research we contact you about.

Please note that this email is separate to the survey so your survey responses will remain completely anonymous.

Key for selection options

11 - On average, how many days a week does a typical person who has had a stroke receive therapy for their upper limb delivered by an occupational therapist?

1
2
3
4
5
6

7
Other
Not known

23 - 1. How often do you use constraint induced movement therapy (CIMT) of the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

26 - 2. How often do you use electrical stimulation for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

29 - 3. How often do you use facilitation/handling (e.g. based on the Bobath concept) of the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

32 - 4. How often do you use functional activity practice for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

35 - 5. How often do you use the Graded Repetitive Arm Supplementary Programme (GRASP) for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

38 - 6. How often do you use mental practice/mental imagery for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

41 - 7. How often do you use mirror therapy for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

44 - 8. How often do you use robot assisted therapy/robotics for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

47 - 9. How often do you use strength training for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

50 - 10. How often do you use video gaming or virtual reality training for someone with arm deficits after stroke?

- Always
- Often
- Sometimes
- Rarely
- Never

SUPPLES UK brief protocol

Target population: Therapists who are fully qualified occupational or physiotherapists currently working clinically with people after stroke

Recruitment: Members of two clinical therapy special interest groups, namely the Association of Chartered Physiotherapists with an Interest in Neurology (ACPIN) and the Royal College of Occupational Therapists – neurological section (RCOT-NS) will be approached to participate in the online survey via the special interest group's email. Both organisations hold email lists of their members who have expressed a wish to be contacted to participate in research studies. These lists can be accessed after scrutiny of the research application and include over 1200 occupational and physiotherapists.

Tool: A link to the online survey (hosted by online surveys, pdf attached) will be distributed directly to participants via email. The first page of the survey informs participants of the study (information sheet) and explicitly outlines that by completing the survey they are giving their consent for their results to be used for research and publication. The survey tool is completed anonymously.

The survey tool is a questionnaire and contains 44 items. It asks for basic demographic information (whilst ensuring anonymity) and then questions the time spent on and the treatments used for different severity of upper limb presentations after stroke where upper limb deficits are defined as (from NIHSS arm item):

MILD= someone who is able to move their arm and maintain an arm position against gravity for 10 seconds without physical support,

MODERATE= someone who has some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support or

SEVERE= someone who has no movement of the arm against gravity OR who can only perform some small movements

Free text boxes are included so that participants can add additional information that they think it is helpful.

Protocol

Peer review - Fully qualified therapists will examine the questionnaire to ensure it is clear and unlikely to cause offence.

Piloting - Piloting of the survey will be undertaken in three therapists to ensure that the questionnaire is clear and easy to complete. Their feedback will be used to refine structure and guide revisions.

Main study - Potential participants will be sent a brief explanation of the study in the main body of an email (sent via ACPIN and R-COTT, text below), an information sheet about the study and a link to complete the online survey (pdf attached). They will be asked to contact the principal investigator should they have any questions about the survey or if they would like to complete it in a different format.

Therapists will be encouraged to participate by postings on online professional networks (e.g. iCSP, professional facebook and twitter groups) and information exchange adverts in professional journals (e.g. Frontline). The survey will be open for 6 weeks with a reminder sent out two weeks prior to the sruvfey closing.

Analysis

Data will be analysed using descriptive statistics. Demographic data will be summarised to indicate the experience and profession of respondents. The percentage of the time spent on treatment will be aggregated using median averages. Frequencies will be used to summarise the Likert scale responses of the use of different treatments and free text comments will be analysed using thematic analysis to identify similar responses. Results will be presented graphically and tabulated and emerging themes will be illustrated by quotes where appropriate.

Email text:

Email text for potential participants (to also be approved by ACPIN, R-COTT)

A Survey of Upper Limb Therapy after Stroke in the UK – SUPPLES UK

Are you a physio or occupational therapist working clinically with people after stroke in the UK?

If so, we are emailing to ask you if you could spare 15 minutes to complete a survey for us. The link to survey is here: survey

If the link does not work, please copy and paste this address into your browser: https://uclan.onlinesurveys.ac.uk/supples-uk-v10

We are a team of physio and occupational therapy researchers based at the University of Central Lancashire in the UK (UCLan). We are undertaking this survey as we want to be able to describe the current practice of therapy for the upper limb in stroke survivors in the UK. Specifically, we want to know about:

- the aims, content and dose of treatment for the upper limb,
- which treatments are used most and least commonly,
- the rationale for using, and not using, specific treatments.

We are contacting you via your professional body interest group as you've given consent to be emailed about research opportunities.

Want to know more? Please read this information sheet at the survey homepage here

By completing the survey you will be helping us understand and describe UK-wide current practice in upper limb rehabilitation after stroke, helping inform guidelines and shaping future research.

Please share: We hope to get as many occupational and physio therapists who work with stroke survivors to complete the survey as possible so please forward this link on to any UK-based physio or occupational therapy colleagues who currently work with people after stroke.

The project has been approved by UCLan's Science Technology Medicine and Health University Research Ethics Committee.

Here is the link to the survey homepage, including the information sheet:
https://uclan.onlinesurveys.ac.uk/supples-uk-v10

Please feel free to forward this email or link on to any colleagues who you think would be suitable to complete the survey.

If you have any queries please contact the Supples UK team at supplesuk@uclan.ac.uk

Thank you for your time.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2/1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3-4
Purpose or research question - Purpose of the study and specific objectives or questions	4/17
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4/21
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4/22
Context - Setting/site and salient contextual factors; rationale**	4/40
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4/40
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5/5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4/42

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Supplemental file and 4/21
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5/23
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	5/8
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	5/8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	NA

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5/23
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5/23

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	8/14
Limitations - Trustworthiness and limitations of findings	8/24

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	11/6
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	10/39

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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Current therapy for the upper-limb after stroke: a cross-sectional survey of UK therapists

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Title: Current therapy for the upper-limb after stroke: a cross-sectional survey of UK therapists

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Abstract

Objectives: To survey the reported content, frequency and duration of upper-limb treatment provided by occupational and physiotherapists for people after stroke in the UK.

Design: An cross-sectional online survey was used. Description and analysis of the data were based on items from the Template for Intervention Description and Replication (TIDieR) (Who, Where, What and How much).

Setting: The online survey was distributed via professional and social networks to UK-based therapists.

Participants: Respondents were occupational or physiotherapists currently working clinically in the UK with people after stroke. Over the 6-week data collection period, 156 respondents opened the survey, and 154 completed it. Respondents comprised 85 physiotherapists and 69 occupational therapists.

Results: Respondents reported treating the upper-limb a median of three times a week (range: 1-7) for a mean of 28 minutes (SD: 19). Most (n=110) stated this was supplemented by rehabilitation assistants, family and/or carers providing additional therapy a median of 3 times a week (range 1-7). Functional training was the most commonly reported treatment for people with mild and moderate upper-limb deficits (>40%). There was much less consistency in treatments reported for people with severe upper-limb deficits with less than 20% (n=28) reporting the same treatments.

Conclusions: This study provides a contemporaneous description of reported therapy in the UK for people with upper-limb deficits after stroke and a detailed template to inform standard therapy interventions in future research. Several evidence-based therapies were reported to be used by respondents (e.g. constraint induced movement therapy), but others were not (e.g. mental imagery). The findings also highlight that the current reported provision of upper-limb therapy is markedly less than what is likely to be effective. This underlines an urgent need to configure and fund services to empower therapists to deliver greater amounts of treatment for people with upper-limb deficits after stroke.

Keywords: Upper limb; rehabilitation, stroke, therapy, survey

Strengths and limitations:

- The survey findings provide key detail about the frequency, intensity and content of therapy for differing severities of arm deficits after stroke
- Unlike other surveys of therapy, the results also describe supplemental activities delivered by rehabilitation assistants and family/carers
- Its findings can be used to design a standard therapy control intervention for future trials of upper-limb interventions
- The findings of the survey are limited by its reliance upon self-report and an unknown response rate

Background

Over 100,000 people have a stroke each year in the UK[1]. Improvements in acute medical care mean that more people survive than ever before, but many need significant rehabilitation to restore function. Whilst two-thirds of people go on to walk independently after stroke, less than half have regained basic functions of the upper-limb by 12 months, which markedly restricts their independence in activities of daily living and reduces their quality of life[2,3]. This makes upper-limb rehabilitation a significant and ongoing priority for people after stroke, clinicians and researchers.

An understanding of what current clinical therapy comprises is vital to allow comparisons to guidelines and the research evidence-base to determine how well research evidence is being translated into routine practice and to inform therapy provision. Furthermore, many trials in stroke rehabilitation compare experimental treatments to a standard or usual therapy, in order to evaluate the potential equivalence or superiority of new interventions. The increasing use of reporting guidelines to describe trials and interventions, such as the TIDieR checklist (Template for Intervention Description and Replication)[4] has encouraged more detailed description of many experimental treatments in research trials. However, the same rigour in reporting is rarely applied when describing standard therapy in studies evaluating rehabilitative interventions in stroke[5]. In published reports of stroke rehabilitation trials, almost half the number of words and references are used to describe and support control treatments compared to the experimental intervention[5]. Underreporting of the components of standard treatment presents problems in the design, interpretation and implementation of the findings of these trials. Firstly, it reduces confidence that participants in a standard therapy control arm received a clinically representative intervention, and so negatively impacts upon the veracity of the trial's results. Secondly, readers of published trials may struggle to interpret differences between groups where one treatment (the standard therapy group) is ill-defined and/or unrealistic and make erroneous conclusions about the superiority of one treatment over another. Thirdly inadequate description means as it cannot be determined if standard therapies delivered across trials are similar, results from multiple studies cannot be compared and the opportunities for synthesis and meta-analysis are reduced.

In the last 10 years, the number of studies of interventions focussed on rehabilitation of the upper-limb after stroke has grown rapidly. This is exemplified by large increases in the numbers of published papers found in updated Cochrane reviews and database searches (for example, a review of virtual reality for the upper limb rose from 12 included studies in 2015 to 22 in 2017, and a Pubmed search using stroke AND upper-limb yielded 354 studies in 2006-2007, increasing to 943 in 2016-17)[6,7]. Despite this increase in research activity, recovery and rehabilitation of the upper-limb after stroke remains a significant challenge, and so it is likely to continue to be a focus of research endeavour for many years to come. Accordingly, accurate reporting of standard therapy/treatments is vital to inform future trial design and to ensure that their results are easily interpretable and reproducible.

In the UK, audits such as the Sentinel Stroke National Audit Programme (SSNAP) provide an indication of temporal elements of therapy (e.g. average treatment time) but do not provide any indication of what treatment comprises[8]. Several studies have sought to describe aspects of therapy provided in rehabilitation of the upper-limb after stroke. Some have reported the content of therapy for the upper-limb used in clinical trials[9,10] but treatments delivered as part of a clinical trial may not necessarily reflect therapy routinely delivered in clinical practice. Similarly, others have developed upper-limb treatment templates to standardise therapy in research trials[11–13] however these templates seek to guide therapy or categorise current treatment, and so do not describe routine clinical practice. Several researchers have observed the number of repetitions, time given to,

and overall dose of therapy occurring during clinical therapy sessions for the upper-limb [10,14–16] and others have observed and recorded the time spent on activities whilst staying in rehabilitation facilities [17–21]. Whilst these observational studies yield perhaps the most objective information about the intensity and provision of therapy, they are based on reports from a small number of international sites which limits their applicability to wider practice in the UK. Crucially, they do not typically provide details of the specific content of therapy.

In the UK, two studies have used surveys to gather information about therapy for the upper-limb after stroke. One national survey in the UK found that exercises are prescribed by nearly all therapists for the upper-limb of people after stroke, but did not investigate the content or duration of treatment undertaken with therapists[22]. Others have surveyed UK stroke teams and used the opinions of expert panels to describe the duration, frequency and content of upper-limb rehabilitation provided by UK stroke teams[23] but did not consider the detailed content of activities nor those performed outside therapy sessions. It is also worth noting that both these studies were conducted several years ago, prior to publication of the latest Stroke Guidelines in 2016[24] which may have altered practice.

Without a contemporaneous and detailed definition, standard therapy in rehabilitation trials for the upper-limb after stroke risk being biased, unrealistic and unreflective of current clinical therapy, affecting the validity and usefulness of the trial results. Furthermore, a description of current clinical practice is needed to evaluate the implementation of research findings into therapeutic practice and to understand 'the state of the art' in upper-limb stroke rehabilitation in the UK. Therefore, this study aims to describe the providers of therapy (who), the reported location (where) content (what), frequency and duration (how much) of upper-limb therapy for people with different severities of arm involvement after stroke in the UK.

Methods

A cross-sectional online survey – the Survey of Upper-limb Therapy after Stroke (SUPPLES UK, Supplementary file) was developed by 2 occupational and 2 physiotherapists and comprised 44 closed, Likert and free text items, was developed using the Online Surveys tool (www.onlinesurveys.ac.uk; formerly known as Bristol Online Surveys). Questions were developed using the current UK stroke guidelines and previous investigations of the provision of upper-limb therapy after stroke [22–24]. The survey and item structure were guided by identified good practice in survey construction and the Template for Intervention Description and Replication (TIDieR) to facilitate replicable reporting of location (where) content (what), frequency and duration (how much) of the reported therapy [4,25]. Sections included:

- Respondent demographics, (where)
- Staff involved in delivery of therapy (who)
- Content (what), frequency and dose of therapy (how much)
- Other activities/therapy provided outside of therapist-led treatments

Respondents were asked to indicate treatments that they typically used for different severities of upper-limb impairments after stroke, defined from the NIH Stroke Scale upper-limb item (0,1=mild-able to lift and hold arm up against gravity for 10 seconds, 2=moderate - some effort against gravity, but the arm cannot get to or maintain the proper position and drifts down to the bed before 10 seconds, 3 and 4= severe – unable to move against gravity or no voluntary movement)[26].

The survey was piloted by three therapists, peer-reviewed and refined according to feedback. The final survey was distributed via professional channels, (Association of Chartered Physiotherapists Interested in Neurology, ACPIN, Royal College of Occupational Therapists- neurological section, RCOT-NS, Physiotherapy Frontline) and social networks (Twitter). It remained open for six weeks (1st July to 13th August 2018).

Respondents were provided with an information sheet (online) and consent was implied by completing the survey. They completed the survey anonymously, having first confirmed they were occupational or physiotherapists and that they were currently clinically working with stroke survivors.

Patient and Public Involvement

Patients and the public were not involved in this research.

The survey gained ethical approval from the Science Technology, Medicine and Health Ethics panel at the University of Central Lancashire (reference number: 869).

Analysis

Demographic details, treatment frequencies and durations were summarised using descriptive statistics. Interval level data were reported using means and standard deviations if they were normally distributed (after testing using Kolmogorov-Smirnov tests), whilst ordinal and nominal data used median and ranges. As some respondents worked across settings, their primary location of work was assumed to be where they spent at least 75% of their time. Where a range was provided by respondents in free-text answers (e.g. 20-30 minutes), the mean was used and weekly frequencies were expressed as a fraction of 7 days a week (e.g. every day= 7). If respondents reported providing treatments more than once a day, this was expressed as a multiple (e.g. twice daily treatment every day=14). Free text answers were initially listed and then coded into themes by one person (RP), and independently verified by another (RS). Any disagreements in coding were resolved by a third person (LC or KJ). The TIDieR framework was used to structure the analysis and presentation of results. This paper reports who provided treatments (Who; physiotherapists, occupational therapists, others), where respondents were based (Where), treatment content (What) and frequency and duration (When and How much). Analyses were undertaken using MS Excel and SPSS version 23.

Results

Respondent demographics

One hundred and fifty-six people completed the two mandatory questions (confirming that they were an occupational or physiotherapist and that they were currently clinically working with stroke survivors at any stage of their recovery in the UK). Two respondents' data were excluded from further analysis as they had more than 50% of data missing (both physiotherapists). Respondents came from all over the UK and Northern Ireland (see Figure 1). A TIDieR checklist was completed using the results (presented in a supplementary file).

Figure 1 – Geographical location of survey respondents (n=154)

Each pin represents a single postcode (first three digits).

Who?

Respondents comprised slightly more physiotherapists (PT) than occupational therapists (OT; 85 physiotherapists, 55%; 69 occupational therapists 45%). The majority of respondents reported an undergraduate degree as their highest qualification (n=79; 51%), 40 had a master's degree (26%) and 9 had a PhD (6%). Nine had completed some master's modules and/or had some postgraduate qualifications (PG cert or similar; 6%) whilst others stated that a diploma was their highest academic qualification (n=15, 10%).

Respondents were a median of 16 years since qualification (range 1-36; n=155). On average, respondents had worked with people after stroke for a median of 10 years (range 1-27; n=154). They reported spending 70% of their clinical time working with people after stroke (SD:30; 8-100; n=153) and of their clinical caseload, they estimated that 38% (SD 18, range:2-80) had severe 34% (10, 18-60) had moderate and 28% (SD 16; 10-80) had mild arm deficits.

Respondents identified other providers of treatment in addition to therapists included rehabilitation assistants (n=44), family/carer/friend (n=47) nursing staff (n=5), volunteers (n=3).

Where?

The majority of respondents were employed in the NHS (80%; n=132) with less than 15% (n=25) working the private sector and 2% working in a voluntary/third sector (n=4) or high education setting (n=3).

Therapists (n=154) worked in a variety of settings. From those that reported spending over 75% of their time in a single setting (n=76) 30 worked in Hyperacute/acute settings (39%), 10 in general inpatient rehabilitation (13%), 2 in intermediate care (3%), 18 in early-supported discharge (24%), 11 in general community (15%) and 5 (7%) in outpatients. The remainder (n=78) did not spend more than 75% of their time in a single setting.

What?

Participants were asked to list treatments that they typically used for people with mild, moderate and severe deficits [26] (defined using the NIH Stroke Scale) of the upper-limb after stroke.

Mild deficits

Respondents reported spending 41% (SD 26, 7-100, n=149) of a typical therapy session on treatments for the upper-limb for people with mild deficits. In free text answers, respondents (n=151) listed 30 treatments/interventions that they would typically use as part of treatment. Those used by more than 10% of respondents are shown in Table 1

Table 1 Treatments used for people with mild upper-limb deficits listed by over 10% of respondents

Treatments	n	%
Functional training	101	67
GRASP	53	35
Active and weighted exercise	29	19
CIMT	25	17
Task repetitive strength training	21	14

GRASP – Graded Repetitive Arm Supplementary Programme, CIMT – Constraint Induced Movement Therapy

Seventy-one percent (n=110) of respondents reported that people with mild deficits of the upper-limb were also given unsupervised activities in addition to that provided during sessions with occupational or physiotherapists. This comprised functional training/practice (n=90), exercise programmes (n=58), GRASP and PRACTISE (Promoting Recovery of the Arm: Clinical Tools for Intensive Stroke Exercise) structured upper-limb exercise programmes (n=49), remedial/table top activities (e.g. theraputty; n=30) and sensory re-education (n=17).

Moderate deficits

In a typical treatment session, respondents reported spending approximately 45% (SD17; 20-90 n=151) of the entire session on upper-limb activities for people with moderate deficits. Respondents (n=150) listed 25 different treatments for people with moderate arm deficits after stroke, those used by more than 10% of respondents are shown in Table 2.

Table 2 Treatments used for people with moderate upper-limb deficits listed by over 10% of respondents

Treatments	**n**	**%**
Functional Training	63	42
Active and weighted exercise	58	38
GRASP	52	35
Mirror box treatment	29	19
CIMT	23	15

GRASP – Graded Repetitive Arm Supplementary Programme, CIMT – Constraint Induced Movement Therapy

Ninety-five percent of respondents (n=143) reported that people with moderate arm deficits were given additional unsupervised activities. These comprised exercise programmes (n=70), practice of functional/everyday tasks (n=50), sensory re-education (n=36), GRASP and PRACTISE structured upper-limb exercise programmes (n=34), mirror therapy (n=14) and positioning (n=14).

Severe deficits

Respondents estimated that they spent 35% (SD19, 10-90, n=149) of a typical treatment session on upper-limb treatments for people with severe deficits. From free text answers, respondents (n=147) listed 16 different treatments for the upper-limb in this group. The treatments reported to be used by over 10% of respondents for this group are displayed in Table 3.

Table 3 Treatments used for people with severe upper-limb deficits listed by over 10% of respondents

Treatments	**n**	**%**
Range of Movement exercises	28	19
Mirror Box treatment	20	14
Functional Electrical Stimulation	20	14

Seventy-nine percent of respondents (n=119) reported that people with severe arm deficits typically received additional unsupervised therapy to that provided by physio and occupational therapists. This included exercise programmes (n=66), Sensory re-education/massage (n=42), positioning (n=39), advice and education (n=33), mirror therapy (n=12) and splinting (n=12).

How much?

Frequency

Respondents reported that occupational and physiotherapists provided treatment for the upper-limb a median of three times a week (range PT: 1-7 days n=153; OT: 1-6 days n=154). The frequency varied depending upon setting (Figure 2) with patients in inpatient settings receiving somewhat more frequent treatment than those in general community and outpatient settings.

Figure 2 Reported median frequency of therapy provided each week according to location

Error bars denote interquartile range.

One hundred and ten respondents stated that treatment by others was provided in addition to occupational and physio therapy, whilst 44 reported that no one else provided additional therapy. For those indicating that additional therapy was provided it was given a median of 3 times a week by rehabilitation assistants (n=47; range 1-7) and on a daily basis by family/carer/friends (range:3-7; n=44).

Duration

Within each therapy session, respondents estimated typically spending a mean of 28.4 minutes (n=154; SD19, range:7.5-80) directly engaged in upper-limb treatments ("time on task"). This varied depending upon where the patient was based (Table 4).

Table 4 Mean reported time spent on upper-limb in treatment session by location

Location	n	Mean time (minutes, SD)
Hyperacute/ acute care	29	21.4 (14.2)
Early supported discharge	18	23.8 (12)
General rehabilitation	10	25.5 (14.4)
Intermediate care	2	25 (7)
General community	10	20.5 (15.2)
Outpatients	5	32 (15.2)

Data of the time spent on treatment in each location is only presented for respondents who reported spending over 75% of their clinical time in this single area (n= 74)

A completed TIDieR checklist is presented in a supplementary file and collated data is presented in tables in Appendix I and II.

Discussion

This study utilised elements of a recognised reporting tool, the TIDieR checklist (presented in a supplementary file)[4], to develop a survey to describe the content of usual therapy reported by occupational and physiotherapists for the upper-limb after stroke. Respondents appeared largely representative of the wider UK therapist population, demonstrating a range of academic

qualifications, geographical location and reported significant experience in stroke rehabilitation. By aligning reported therapy practice across the UK to items of the TIDieR checklist, the survey findings can be used to design clear and replicable standard therapy control interventions to inform future research trials. Furthermore, by providing a detailed description of reported current practice this study highlights gaps between recommended treatments from guidelines and their implementation in clinical settings, guiding future research and rehabilitation service configurations.

However, the survey findings have several limitations. The response rate of the survey is not known because it was distributed electronically via multiple channels. The ACPIN database, which was one channel through which it was circulated, contains over 1000 members, suggesting that the survey's response rate was relatively low but not unexpected for this type of survey[27]. Efforts were made to increase responses through reminder emails and the use of the professional organisations for distribution provided credibility and anonymity. As the sample size was over 150 the sampling error was reduced[27] but should still be acknowledged. It is also worth of note that there were very little missing data, with only two (subsequently excluded) respondents omitting more than 50% of items. This suggests that although some people chose not to open the survey, those that did completed it diligently. It is also likely that respondents were motivated and interested in upper-limb rehabilitation. This and the greater number of physiotherapist respondents and the relatively long average time since qualification (16 years) may introduce some unavoidable bias in responses which should be considered when interpreting the results.

Severe and moderate arm deficits were the largest proportion treated most frequently by respondents, with mild deficits being seen much less often. Despite a slight preponderance in moderate severity arm impairments in the current study, these proportions appear broadly similar to those reported by others after stroke, although direct comparison between studies is hindered by the range of outcome tools used to classify to arm function [28,29] . The survey found that, on average, respondents reported providing upper-limb therapy for 28 minutes three times a week, although both these parameters varied depending on the setting. An interesting finding was that the reported average time of upper-limb treatment per session (28 minutes) was considerably more than that reported in observational studies. In systematic reviews, between four to 17 minutes of therapy was spent on upper-limb activity and/or other treatments in a typical session[30][10]. The greater intensity of therapy reported in this survey could suggest a selection bias as those therapists who were motivated and able to provide more upper-limb therapy might have been more likely to complete the survey. It could also indicate, as observed by others, that therapists may have over reported or struggled to accurately recall the actual time spent on treatment [31]. However, the differences in findings between studies might reflect different interpretations as to what upper-limb therapy actually comprises in this study as some therapists may have considered the time to include activities where the upper-limb was likely to benefit from therapy, but was not the direct target of intervention (e.g. aerobic exercise) [32,33]. This ambiguity might be an inevitable limitation of the current study's findings, but focus on content of therapy and who delivered it attempted to minimise this effect by providing some guidance to therapists on what did, and what did not, constitute therapy.

An unanticipated and novel finding is the majority of respondents noted that they provided additional activities and that others supplemented therapy for people after stroke. On average this was provided on a daily basis by family/carers (n=44) and three times a week by rehabilitation assistants (n=47). This is the first study to highlight the provision of additional therapy as a component of standard therapy and indicates that this extra input should be recognised when considering replicating standard treatment in trials. Despite this, the findings of this survey indicate

that the reported overall dose of therapy is relatively small when compared to what is known to be effective from animal models of stroke rehabilitation[34] and so may not realise the potential for recovery. This argument is supported by findings from other studies; several large, well-conducted trials offering similar amounts of upper-limb therapy to those reported in the current study found minimal benefit[35,36] whilst trials that used higher doses reported meaningful and significant changes[37,38]. In addition to research trials, large improvements in upper-limb functioning have been reported in an NHS-funded clinical service (the Queen's Square Upper-limb Programme) that delivers 90 hours of multidisciplinary upper-limb rehabilitation over three weeks[33]. When the intensities of therapy in these studies are compared to those measured in observational studies[32,39], SSNAP data[8] and the current study, they emphasise that service provision for rehabilitation of the upper-limb after stroke needs radical alteration if it is to empower therapists to provide effective therapy and maximise recovery for people after stroke. Further research is therefore urgently needed to find ways to upscale services so that they can deliver greater intensities of high-quality, evidence-based therapy for the upper-limb that can be provided in clinical practice.

The findings indicate that several well-evidenced and recommended clinical treatments (e.g. the Constraint Induced Movement Therapy and the Graded Repetitive Arm Supplementary Programme) were reported to be used by many respondents. Other treatments with an emerging evidence base were not reported to be used often (e.g. FES, mental practice). Interestingly, repetitive task training, a treatment in which participants repeatedly practice a task or goal oriented movement, was not explicitly listed by any participant, despite being recommended in guidelines and supported by a relatively robust evidence base [24,40]. However, it is possible that respondents' use of 'functional training' to describe their treatments could have been analogous to repetitive task training, but this cannot be verified. Some respondents did report using 'task specific strength training' (mild: n=21; moderate: n=11) but, as this terminology is not widely utilised in rehabilitation literature it is unclear what it comprises. The focus of therapy towards functional activities found in this study supports other reports of practice in the UK[23] and treatments those for mild and moderate upper-limb deficits showed considerable similarities between respondents. Whilst others have reported somewhat greater consensus for the use of functional activities in therapy (over 88% for mild and moderate deficits), this may be due to different survey approaches and the use of an expert panel to interpret and express consensus on the data[23]. In contrast, there was a notable lack of consistency in the treatment choices reported for people with severe deficits of the upper-limb; the most commonly given treatment (range of motion) was only listed by 19% of 107 respondents. This may reflect therapists' uncertainty about the recovery of the severely impaired upper-limb and the current absence of specific guidance and established effective therapies for rehabilitation after severe stroke[41]. It is also possible that the variability in treatments for those with severe deficits is because of the influence of other factors which tend to accompany more severe deficits after stroke (for example worse pre-stroke status, older age and medical complications). Indeed, it has been found that patients who had a milder stroke, were younger, male, had fewer medical complications and had received thrombolysis tended to receive more intensive therapy after stroke[42]. These findings highlight that better understanding of the factors that influence clinicians' professional decision making about treatment content and intensity is worthy of further investigation to guide clinical care.

The findings also showed that other evidence-based and recommended treatments (such as mental imagery) are not widely implemented in clinical practice[24]. This is perhaps not surprising as only a small fraction (2.5%) of published stroke rehabilitation research in journals evaluate the implementation of evidence-based interventions into health care practice[43]. This indicates that

further investigation is warranted to determine why some treatments are implemented and others are not and suggests that a greater focus on how recognised effective treatments can become part of routine clinical care is needed.

Conclusions

This survey has identified the commonly reported upper-limb treatments that are provided for people after stroke by occupational and physiotherapists. These results are not intended to provide an exemplar or template for clinical practice or represent best practice and are limited by an unknown response rate and the self-reported nature of the data. However, they can be used to reflect current practice in the UK and provide a detailed point of reference to aid the development of standard therapy interventions in research trials.

The findings indicate that some evidence-based treatments appear to be more widely implemented in routine clinical practice than others and that whilst there is considerable consensus in the treatments used for mild and moderate upper-limb deficits, there was much less consistency in the treatments used with people with severe deficits. The results also indicate that the intensity of therapy is less than that shown to be effective in rehabilitation studies.

Future work could seek to identify the optimally effective treatments for different severities of upper-limb involvement after stroke and qualitatively explore the rationale for treatment selection. Finding ways to deliver more intensive therapy in practice is also urgently required and the development of new treatments should explicitly consider how they can be adopted into clinical practice. The findings of the current study contribute to these endeavours by providing a detailed description of self-reported, clinically realistic upper-limb therapy which can inform the design, interpretation and implementation of future stroke rehabilitation research.

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Author Contributions

RS developed the idea and undertook analysis of the results and drafted the paper

RP conducted analysis of the data and drafted the paper

LC developed the idea, oversaw analysis and drafted the paper

KJ developed the idea, oversaw analysis and drafted the paper

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Competing interests

The authors have no competing interests.

Data sharing

At this stage, no other data is publicly available for this study. We are actively seeking ways to make it available and plan, if it is accepted for publication, that it will be.

Appendices

1 The SUPPLES-UK questionnaire

2 Protocol for the study

3 Complete TIDieR checklist

4 Supplementary Tables I and II

5 Figures 1 and 2

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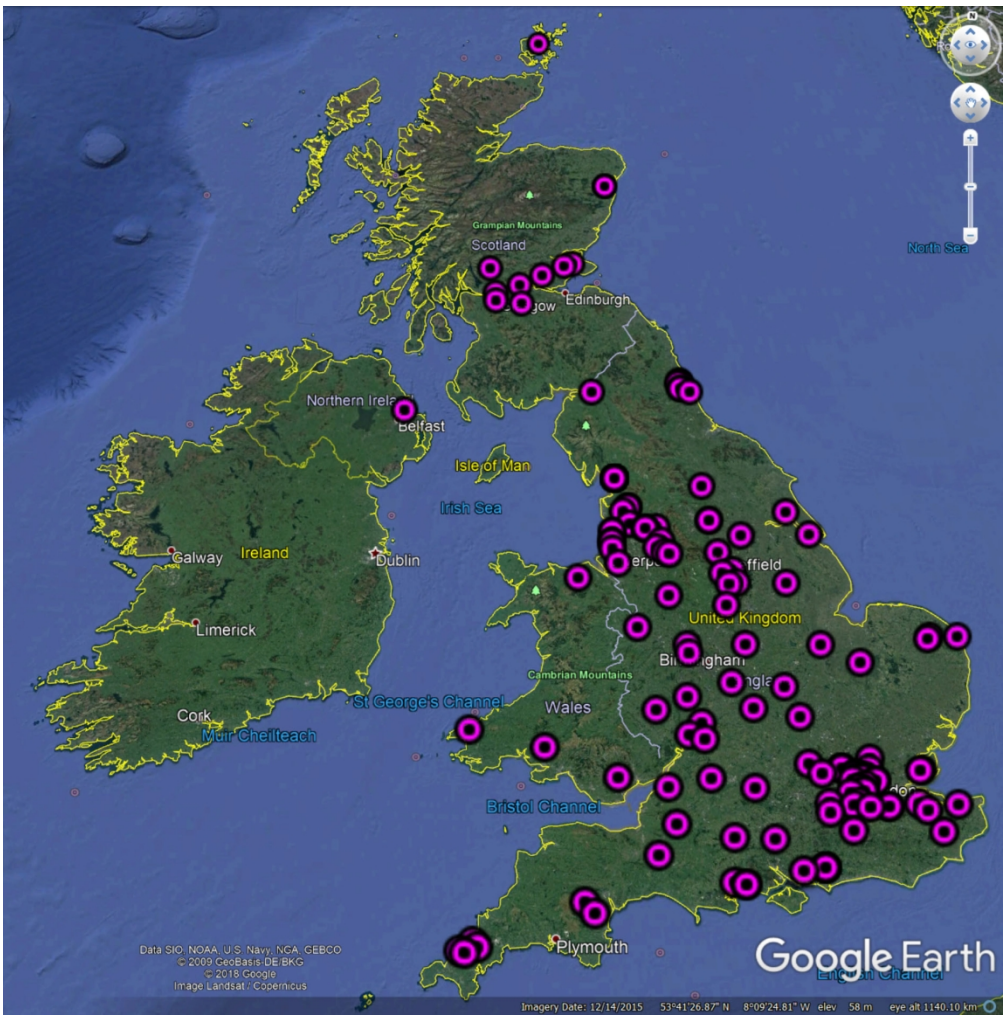

Figure 1 - Geographical location of survey respondents who completed this question (n=144) Legend - Each marker indicates the postcode area

158x160mm (300 x 300 DPI)

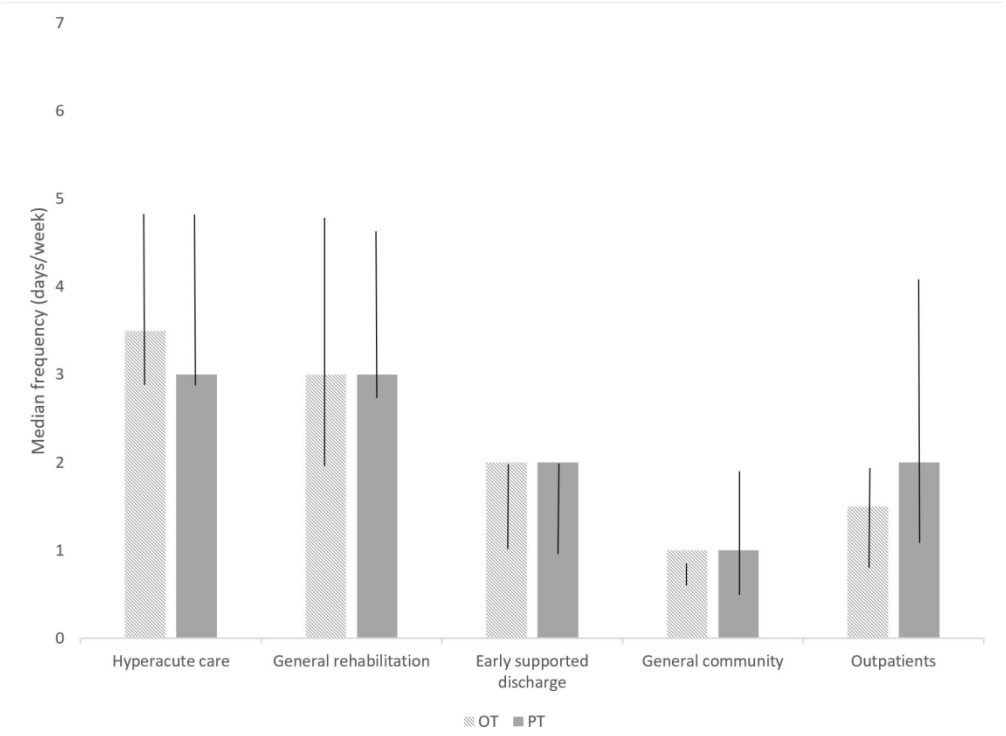

Figure 2 Reported median frequency of therapy provided each week according to location
Legend - Error bars denote interquartile range

151x112mm (300 x 300 DPI)

SUPPLES-UK

Page 1

Thank you for considering completing this survey.

We are a team of occupational and physiotherapy researchers, based at the University of Central Lancashire (UCLan) and we want to describe current UK physio and occupational therapy practice in stroke rehabilitation. By completing this survey, your answers will provide vital information so that we can understand which treatments are being used, how treatments are used and identify factors that influence therapy practice in 2018. This information sheet will tell you more (click here: information sheet)

Before you start: The survey may take around **15** minutes. Although some questions may seem long, please provide as much detail as you can so we can produce a really accurate picture of UK therapy practice.

Completing the survey: Please answer as many questions as you can. You must complete the survey in one sitting as it will not save partly completed questions.

Unsure of how to answer? We know that treatments are personalised to each patient but please answer questions based on your **'average'** practice. Some questions are also more complicated than others. Those that are have guidance to help you answer. To see this please click the 'more info' button beneath the question.

Your privacy: None of your personal details are known to the research team. This survey

will not ask you to share any information that could be used to identify you and all your answers are completely anonymous. All data from this study will be stored securely on password protected PCs/networks. This study has been approved by UCLan's Science Technology Health and Medicine Ethics Committee. You do not need to complete a consent form to participate. By completing and submitting the survey, you are giving consent for us to use your answers for this study.

Want to know more? Please read this information sheet. If you still have any queries, please contact the team (supplesuk@uclan.ac.uk).

Please share! We want as many physio and occupational therapists who work with people after stroke in the UK to complete the survey - please feel free to share the survey link with them.

Section 1 - About you

Are you a Physio or Occupational Therapist working in the UK? ✱ *Required*

- ○ Physiotherapist
- ○ Occupational Therapist
- ○ Not a physio or occupational therapist OR not working in the UK

How many years have you been qualified?

What is your highest academic qualification?

- ○ PhD
- ○ MSc, MA or MEd

- BSc
- Diploma
- Other

If you selected Other, please specify:

How many years have you worked with people who have had a stroke?

Do you currently work clinically with stroke survivors with upper limb deficits at any stage of their rehabilitation? ✱ *Required*

- Yes
- No

Where are you currently employed? *Optional*

More info

- [ ] NHS
- [ ] Private sector
- [ ] Voluntary/Third sector
- [ ] Higher Education
- [ ] Other

If you selected Other, please specify:

Please tell us the first part of the postcode for your primary place of work in the UK (e.g. PR1)

In which setting/s do you usually work? Please provide an approximate percentage of the time you spend in each setting (e.g. 40% Acute Stroke Unit, 60% Neuro-outpatients).

More info

	Percentage of time spent in this area
Hyperacute/Acute Stroke Unit	
General rehabilitation Ward	
Intermediate Care	
Early supported discharge	

General Community	
Neuro-outpatients	
Other	

On average, what percentage of your **clinical** time is spent working with people who have had a stroke?

We are interested in the time you estimate you spend directly engaged in treating people who have had a stroke. Please try to give an accurate and honest approximation.

Within a single treatment session **on average** how many ***minutes*** would you typically spend **directly undertaking *upper limb* treatment** with a person who has **any severity** of upper limb deficits after stroke that is linked to agreed goals (i.e. “time on task” so not including paperwork, MDT meetings, transporting patient to gym etc.)?

More info

Please use this space to tell us anything you feel is relevant to this question.

Section 2 - Delivery of rehabilitation for the upper limb after stroke

We appreciate that the treatment approach used with every patient will differ according to his or her needs and goals after a stroke. However, in this section we are interested in your "***broad approach***" to treatment. Therefore, we would like you to tell us about your **usual practice** when working with a person with upper limb deficits after stroke.

On average, how many days a week does a **typical** person who has had a stroke receive **therapy for their upper limb** delivered by an **occupational therapist**?

If you selected Other, please specify:

On average, how many days a week does a **typical** person who has had a stroke receive **therapy for their upper limb** delivered by a **physiotherapist**?

If you selected Other, please specify:

Section 2 - Delivery of rehabilitation for the upper limb after stroke

After stroke, people will have very varied abilities with their upper limb. For the purposes of this survey, we have divided people into three groups based upon their motor arm function. These are **MILD, MODERATE AND SEVERE** (based upon the NIHSS categories - motor arm).

Please estimate what **percentage** of the people that you see after stroke have arm deficits that would be considered to be:

	%
MILD: someone who is able to move the arm and maintain an arm position against gravity for 10 seconds without physical support	
MODERATE: someone who has some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support	
SEVERE: someone who has no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders)	

Within a **typical** treatment session, what **percentage of the entire treatment session** would you spend on treatments for the upper limb for each of these presentations?

More info

	%
MILD: someone who is able to move the arm and maintain an arm position against gravity for 10 seconds without physical support	
MODERATE: someone who has some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support	
SEVERE: someone who has no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders)	

Outcome Tools

Please list any of the outcome tools or measurements you would commonly use to indicate upper limb ability after stroke.

Key factors affecting upper limb treatment time

We are interested in the factors that **you think typically affect** the direct treatment time of the upper limb. Please tell us how much the following factors influence the time **you spend** undertaking **direct** treatment of the upper limb of a person with arm deficits after stroke.

Please don't select more than 1 answer(s) per row.

	A lot	A little	Not at all
Requirements of external audit (e.g. SSNAP)	☐	☐	☐
Evidence informing treatment dose	☐	☐	☐
Patient factors (e.g. availability and condition)	☐	☐	☐
Staffing levels	☐	☐	☐
Designated time for therapy (e.g. using timetabling)	☐	☐	☐
Time spent in information exchange (handovers, ward round)	☐	☐	☐
Competing priorities (e.g. walking/mobility practice)	☐	☐	☐
Other non-patient contact activities (e.g. organising /ordering equipment)	☐	☐	☐

Please use this space to tell us anything else you feel is relevant to this question. For instance, please tell us if some of these factors have a negative effect (e.g. meaning you spend less time than you would like on upper limb rehabilitation) and/or if other factors that influence the time you spend on upper limb treatments for people after stroke.

Does a person who has upper limb deficits after having a stroke receive any other treatment for their upper limb **in addition** to that received during physiotherapy or occupational therapy?

- Yes
- No

If yes, please tell us who provides this and how often it occurs (e.g. once a week, everyday, three times a day everyday). If you do not know how often it occurs please still tell us about who is involved.

More info

Section 3 - Treatments for the upper limb

In this section, we are interested in the interventions you would use for people who have had a stroke who have mild, moderate and severe arm deficits.

MILD DEFICITS: Please list the treatment interventions you use most often for a person who has had a stroke and is **able to move their arm and maintain an arm position against gravity for 10 seconds without physical support.**

Do you routinely ask a people who have MILD arm deficits to undertake activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

MODERATE DEFICITS: Please list the treatment interventions you use most often for a person who has had a stroke and who has **some movement of the arm but cannot maintain an arm position against gravity for 10 seconds without physical support.**

Do you routinely ask a people who have MODERATE arm deficits to undertake activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

SEVERE DEFICITS: Please list the treatment interventions that you use most often for someone after a stroke who has **no movement of the arm against gravity OR who can only perform some small movements (e.g. shrugging shoulders**)

Do you routinely ask people with **SEVERE** arm deficits to undertake unsupervised activities for their upper limb in addition to therapist led treatment?

- Yes
- No

If Yes, please tell us what these activities might comprise. If No, please use this space to tell us anything you feel is relevant.

Please use this space below to provide us with any extra information that you think we may find useful. For instance, you may want to tell us about why you use the treatments you use, or why you have chosen not to use some treatments.

Section 4 - Specific Treatments

We are interested in if and how you use **ten** specific treatments. Please indicate how frequently you utilise the following interventions when working with people after stroke with **any severity** of upper limb deficits. If you answer **'never'** to indicate you don't use a treatment you will be re-directed to a question to tell us why.

Section 4 - Specific Treatments

1. How often do you use constraint induced movement therapy (CIMT) of the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

2. How often do you use electrical stimulation for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

3. How often do you use facilitation/handling (e.g. based on the Bobath concept) of the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

4. How often do you use functional activity practice for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

5. How often do you use the Graded Repetitive Arm Supplementary Programme (GRASP) for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

6. How often do you use mental practice/mental imagery for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

7. How often do you use mirror therapy for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

8. How often do you use robot assisted therapy/robotics for the arm for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

9. How often do you use strength training for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

10. How often do you use video gaming or virtual reality training for someone with arm deficits after stroke?

Rationale for not using a treatment

If you never use this treatment, please indicate why from the reasons below.

- I do not have access to this treatment
- I have not been trained in this treatment
- I think there is insufficient evidence for this treatment
- Other

If you selected Other, please specify:

Section 4 - Specific Treatments

Please use this space to tell us about any other treatments that you use and how often you use them.

Additional information about your practice

Please use this space to tell anything else you think is relevant.

Thank you for completing this survey!

We really appreciate the time you have taken to help us understand current therapy practice for the upper limb in the UK.

We are interested in undertaking further research into rehabilitation for the upper limb after stroke and current therapy practice.

If you would like to be kept informed and potentially participate in this work, please email us at supplesuk@uclan.ac.uk.

By emailing us you are consenting to be contacted about future work but are not obliged to take part in any other research we contact you about.

Please note that this email is separate to the survey so your survey responses will remain completely anonymous.

Key for selection options

11 - On average, how many days a week does a typical person who has had a stroke receive therapy for their upper limb delivered by an occupational therapist?

1
2
3
4
5
6

7
Other
Not known

23 - 1. How often do you use constraint induced movement therapy (CIMT) of the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

26 - 2. How often do you use electrical stimulation for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

29 - 3. How often do you use facilitation/handling (e.g. based on the Bobath concept) of the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

32 - 4. How often do you use functional activity practice for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

35 - 5. How often do you use the Graded Repetitive Arm Supplementary Programme (GRASP) for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

38 - 6. How often do you use mental practice/mental imagery for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

41 - 7. How often do you use mirror therapy for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

44 - 8. How often do you use robot assisted therapy/robotics for the arm for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

47 - 9. How often do you use strength training for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

50 - 10. How often do you use video gaming or virtual reality training for someone with arm deficits after stroke?

Always
Often
Sometimes
Rarely
Never

TiDieR

Describing current therapy in the UK for the upper limb after stroke

Details:	Current Upper Limb therapy
Why:	NA
What (material):	NA
What (procedures):	**Mild (UL NIHSS =0 or 1)** Functional training GRASP Active and weighted exercise CIMT Task repetitive strength training **Moderate (UL NIHSS =2)** Functional Training Active and weighted exercise GRASP Mirror box treatment CIMT **Severe (UL NIHSS = 3 and 4)** Range of Movement exercises Mirror Box treatment Functional Electrical Stimulation
Who provided:	**Occupational Therapists** **Physiotherapists** **Additional therapy** Rehabilitation assistants Family/Carer/Friend
How (mode of delivery; individual or group):	Face to face.
Where:	In the UK. Hospital based: Hyperacute/Acute Stroke Unit, General Rehabilitation, Community based: Early supported discharge, General Community, Outpatients
When and how much:	

Form saved

Who delivered therapy?	Where?	How much – Frequency (sessions/week, median, range)	Duration (minutes/session, mean, SD)
Occupational Therapists			
	Hyperacute/Acute Stroke Unit	3.5 (4)	27 (17)
	General Rehabilitation	3 (3)	29 (15)
	Early supported discharge	2 (2)	28 (13)
	General Community	1 (1)	25 (13)
	Outpatients	1.5 (1)	48 (4)
Physiotherapists			
	Hyperacute/Acute Stroke Unit	3 (4)	17 (10)
	General Rehabilitation	3 (3)	16 (12)
	Early supported discharge	2 (3)	23 (12)
	General Community	1 (3)	19 (17)
	Outpatients	2 (1)	22 (8)
Additional therapy			
	Rehabilitation assistants	3 (6)	
	Family/Carer/Friend	7 (4)	

Tailoring: NA

How well (planned): NA

Form saved

Appendix I

Table to show TIDieR checklist items Who, Where and How much for upper limb treatments

Who delivered therapy? (n)	Where?	How much – Frequency(sessions/week, median, range)	How much – Duration(minutes/session, mean, SD)
Occupational Therapists (69)	Hyperacute/Acute Stroke Unit	3.5 (4)	27 (17)
	General Rehabilitation	3 (3)	29 (15)
	Early supported discharge	2 (2)	28 (13)
	General Community	1 (1)	25 (13)
	Outpatients	1.5 (1)	48 (4)
Physiotherapists (85)	Hyperacute/Acute Stroke Unit	3 (4)	16.8 (10)
	General Rehabilitation	3 (3)	16 (12)
	Early supported discharge	2 (3)	23 (12)
	General Community	1 (3)	19 (17)
	Outpatients	2 (1)	22 (8)

Appendix II

Table to show 'What?' TIDieR item: Treatments reported by over 10% of respondents for different severities of upper limb deficits

Severity	Mild (UL NIHSS score of 0 or 1)	n	Moderate (UL NIHSS score =2)	n	Severe (UL NIHSS: 3 and 4)	n
Treatments	Functional training	101	Functional Training	63	Range of Movement exercises	42
	GRASP	53	Active and weighted exercise	58	Mirror Box treatment	20
	Active and weighted exercise	29	GRASP	52	Functional Electrical Stimulation	20
	CIMT	25	Mirror box treatment	29		
	Task repetitive strength training	21	CIMT	23		

UL NIHSS – Upper limb National Institute of Health Stroke Scale upper limb item: 0,1= able to lift and hold arm up against gravity for 10 seconds, 2= some effort against gravity, but the arm cannot get to or maintain the proper position and drifts down to the bed before 10 seconds, 3 and 4= unable to move against gravity or no voluntary movement. GRASP – Graded Repetitive Arm Supplementary Programme CIMT – Constraint Induced Movement Therapy

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2/1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3-4
Purpose or research question - Purpose of the study and specific objectives or questions	4/17
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	4/21
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	4/22
Context - Setting/site and salient contextual factors; rationale**	4/40
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	4/40
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5/5
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4/42

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Supplemental file and 4/21
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	5/23
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	5/8
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	5/8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	NA

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5/23
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5/23

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	8/14
Limitations - Trustworthiness and limitations of findings	8/24

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	11/6
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	10/39

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:
O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388